MSQLI

Multiple Sclerosis Quality of Life Inventory:
A User's Manual

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Inventory:
A User's Manual

Developed by:
The Consortium
of Multiple Sclerosis Centers
Health Services Research
Subcommittee

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Foreword

The Multiple Sclerosis Quality of Life Inventory (MSQLI) was developed as a comprehensive outcomes assessment battery. It evolved in a series of two contracts funded by the Health Care Delivery and Policy Research Program of the National Multiple Sclerosis Society (NMSS) to the Consortium of Multiple Sclerosis Centers (CMSC). Additional funding for the second of the two projects was provided by the Multiple Sclerosis Society of Canada (MSSC).

Development of the MSQLI began when the CMSC recognized the need to develop and test health-related quality of life measures for persons with multiple sclerosis (MS). This need reflects, in part, the broad range of outcomes that are of interest to health care professionals and individuals with MS. These outcomes include not only medically oriented goals such as improvement in walking and spasticity but also a variety of quality of life goals such as improving emotional state and enhancing social support. As such, the MSQLI is designed to supplement rather than replace traditional MS outcome measures such as the Expanded Disability Status Scale or magnetic resonance imaging.

In developing the MSQLI, the goal of the investigators was to provide a quality of life measure specifically tailored to MS but one that could easily be related to work done with other medical conditions. For this reason, the MSQLI utilizes the SF-36, a widely used generic quality of life instrument, as well as scales specific to MS problems such as bladder dysfunction and fatigue. Wherever possible, published and well-established scales have been used. However, in some instances, we have had to modify these or create our own. The MSQLI thus represents an attempt to achieve an optimal mix of the general and the specific, the old and the new.

It is anticipated that the MSQLI will be most useful to MS researchers undertaking clinical studies where there is a need to assess a wide range of outcomes. For example, the MSQLI might be used in a clinical trial to evaluate differences over time in quality of life between patients treated with the active drug and those treated with placebo. The MSQLI could also be used as one of the methods to evaluate differences in outcomes between alternative service delivery models such as an adult day program vs nursing home care. The possible uses of the MSQLI are only limited by the imagination of the investigator.

Unlike some quality of life measures, the MSQLI does not provide a single number to summarize quality of life. There is some controversy concerning whether or not a single number can adequately capture the richness and complexity inherent in a concept such as "quality of life". The MSQLI provides several scores, each of which represents one specific facet of quality of life. It is the firm belief of the authors that this multifaceted approach makes the most sense. However, for those investigators interested in utilizing a more global approach to quality of life, the section on Administration and Scoring provides instructions for deriving a *physical component summary scale* and a *mental component summary scale* from the 36 items making up the SF-36.

The MSQLI forms a comprehensive but relatively brief assessment package consisting of 138 items organized into 10 scales. The MSQLI can be administered in **45** minutes in most cases. Wherever possible, it should be used in its entirety. However, some investigators may want to utilize

only parts of the package. To accommodate such users, the MSQLI has been supplied as a set of separate scales or "modules" each of which can be used alone. In addition, several of the scales have been supplied in two versions: a full-length version as well as an abbreviated version, reducing administration time for the reduced set of **81** items to approximately **30** minutes.

This user's manual provides all the information and materials needed by investigators who are interested in utilizing the MSQLI in their studies. Included is information on the development of the MSQLI, the background of the various scales making up the MSQLI, detailed instructions for administration of the instruments, and algorithms for scoring each scale. In addition, copies of all the MSQLI scales are included so that the user can photocopy these and use them immediately. Absent from this manual is detailed information on the field testing of the MSQLI and analysis of the resulting data. These technical materials have been omitted in order to make this manual more user-friendly, since investigators interested in utilizing the MSQLI may not feel the need to plow through mountains of statistics. However, for those interested in all the details, technical information on the MSQLI is available by contacting Dr. Nicholas LaRocca at the NMSS, telephone: (212) 476-0414. It is hoped that you will find the MSQLI an easy to use and scientifically productive resource. Your comments and suggestions are most welcome and may be forwarded to Dr. LaRocca at the NMSS.

Background and Development

1.   Phase I of Development: Constructing the MSQLI

The Multiple Sclerosis Quality of Life Inventory is an outcomes assessment inventory developed in two phases in projects sponsored by the Consortium of Multiple Sclerosis Centers (CMSC) and funded by the Health Care Delivery and Policy Research Program of the National Multiple Sclerosis Society (NMSS). Funding was additionally provided by the Multiple Sclerosis Society of Canada (MSSC).

The project was initiated because of the need to develop health-related quality of life (HQL) measures specifically for patients with MS. In Phase I, the investigators reviewed existing HQL literature, both MS-specific and generic, and selected candidate measures for the inventory. These measures were reviewed by panels of clinical-research neurologists and allied clinicians who treated MS patients, and by individuals with MS and their caregivers. Members of the two health professional panels were selected for expertise in MS assessment and clinical intervention. Patient and caregiver panelists were selected by CMSC center directors who solicited participation from individuals who fit detailed descriptions of key characteristics relevant to this panel. The final consumer panel consisted of males and females with mild to moderate physical disability but little or no cognitive impairment, and male and female caregivers of cognitively-impaired individuals with MS.

A key Phase I goal was identifying HQL domains relevant to individuals with MS and sampling them at an appropriate range and depth. Thus panelists were asked to critically review candidate measures with respect to: 1) domains that should be included in the inventory but were not; 2) domains that were inadequately sampled; and 3) unclear questionnaire instructions. Panelists used a standardized format for critical review and their ratings and comments were reviewed by the investigative group in detail. Items were added when 20% of *either* the neurologist, allied health professional or consumer panels indicated a given domain was insufficiently sampled. Suggestions from panelists for supplementing existing content were reviewed and new items were then resubmitted to the critical panelists for review. After reviewing and reevaluating the new items, the panelists were polled again. This procedure continued until an approval criteria of > 80% was achieved in all three panels. Table 1 provides a list of domains and responses from the respective panels. As can be seen, panelists identified insufficient sampling in several domains, with additions consequently made to the inventory. Several other areas identified by panelists were, in the investigators' opinion, relevant to *living* with MS but not to assessing treatment outcomes. These included: knowledge and beliefs about MS; the impact of MS on life decisions; daily activity configuration; dietary practices; coping strategies; and participation in voluntary health groups. While noting their relevance, the investigators deferred the study of these domains for subsequent investigations.

2.   Phase II of Development: Field Testing the MSQLI

In Phase II the MSQLI candidate measures were field tested with 300 persons with MS from four major MS comprehensive care centers. The psychometric characteristics of the field data were analyzed and a reduced set of items, sufficiently brief for administration in clinic settings, were derived. Before the field test began, at the NMSS's suggestion, a distinguished advisory committee reviewed and provided consultation on the project. The committee consisted of: John Ware, Ph.D., Health Institute, New England Medical Center; Robert Kaplan, Ph.D., University of California, San Diego; Sarah Minden, M.D., Abt Associates; and Christopher Bever, M.D., University of Maryland. After a thorough review in September, 1993, several modifications to the instrument reflected a more focal orientation to outcomes assessment. Some alterations were also made to the planned statistical analyses. At the committee's suggestion, the investigative group was joined, at this time, by a distinguished clinical-research neurologist, Don Paty, M.D. of the University of British Columbia.

The Phase II field test results are reported in a technical report that is available by call Dr. Nicholas LaRocca at the NMSS at (212) 476-0414. In the following review, emphasis is placed on: describing instrument domains; the theoretical basis of these domains; scales selected to assess them; and the characteristics of these scales.

3.   Description of the Scales Making up the MSQLI

The MSQLI consists of the following 10 scales containing a total of 138 items. Four of the scales, indicated by an *asterisk, are also available in abbreviated 5 item versions. These abbreviated versions are scientifically sound and reduce the total number of items to 81. However, the shortened scales do not provide as much information as the longer versions. They were constructed to assist users of the MSQLI who may be working under severe time constraints. Use of the four abbreviated scales reduces administration time from 45 to 30 minutes. The full-length versions of the scales should be used whenever possible. The background and development of each scale are described in this section. Information on administration and scoring appears in the section that follows this one.

> **Health Status Questionnaire (SF-36) - 36 items**
> **Modified Fatigue Impact Scale (MFIS) - 21 items***
> **MOS Pain Effects Scale (PES) - 6 items**
> **Sexual Satisfaction Scale (SSS) - 5 items**
> **Bladder Control Scale (BLCS) - 4 items**
> **Bowel Control Scale (BWCS) - 5 items**
> **Impact of Visual Impairment Scale (IVIS) - 5 items**
> **Perceived Deficits Questionnaire (PDQ) - 20 items***
> **Mental Health Inventory (MHI) - 18 items***
> **MOS Modified Social Support Survey (MSSS) - 18 items***
>
> ***(Abbreviated 5 item versions of these scales are also available)**

a) Health Status Questionnaire (SF-36)

The General Health Survey of the Medical Outcomes Study (Stewart, Hayes and Ware, 1988) is probably the most widely used generic health status measure in the HQL literature. The Short Form-36 (SF-36) has been used in a great variety of clinical and research settings (Stewart et al., 1989; Stewart, Hayes, Burnam and Rogers, 1989) and has demonstrated a capacity to effectively discriminate between subjects with different chronic conditions and between subjects with different severity levels of the same disease. The SF-36 has also demonstrated a capacity to detect significant treatment effects in a variety of patient populations. For these reasons, the SF-36 is a useful measure to employ in comparing the current health status of different illness-affected populations as well as their responses to specific treatments.

Blanket assumptions, however, should *not* be made that generic measures, like the SF-36, adequately or comprehensively measure status and treatment effects in disease-specific populations, such as MS patients. The development of separate measures specifically suited for MS patients was the primary MSQLI project goal. Our field test results enable investigators and clinicians to *begin* estimating the appropriate applications for the SF-36 with respect to the MS population. Estimations of SF-36 performance, as well as the performance of other MSQLI subscales, however, are limited by the fact that our field test data is cross-sectional whereas outcomes evaluations are mostly longitudinal. *Items perform differently in assessing change in patients <u>over time</u> (Time 1 vs. Time 2),vs. evaluating differences, cross sectionally, in groups assessed at a <u>single point in time</u>.* As such, the MSQLI investigative team was cautioned by the Advisory Committee to abbreviate by no more than 25% during Phase II. Dr. John Ware, one of the primary developers of the SF 36 and an Advisory Committee member, was particularly assertive about the need to field test HRQL items *longitudinally* to properly evaluate their psychometric validity in assessing changes in status over time (for example, in response to treatment). *Because items that seem redundant in cross sectional analyses sometimes prove validly sensitive in evaluating change over time,* this cautionary principle is especially appropriate to evaluating the relative value of using the SF-36 alone vs. the MSQLI as a whole in clinical treatment trials. Until further longitudinal studies are undertaken where SF-36 measurement alone is compared with the full MSQLI, we strongly advise use of the <u>full</u> MSQLI in assessing outcomes in individuals with MS.

b) Modified Fatigue Impact Scale (MFIS)

Fatigue, a common and frequently disabling symptom in MS, has been shown to interfere with activities of daily living and to rank with the most troubling symptoms reported by MS patients (Kraft, Freal, and Coryell, 1986). Several studies have confirmed the prevalence and importance of fatigue as an MS symptom, particularly in relation to mental health (Ritvo, Fisk, Archibald, Field and Murray, 1996; Krupp, Alvarez, LaRocca and Scheinberg, 1988; Carter, Sciarra and Merritt, 1950; Clifford and Trotter, 1984). These results are congruent with Phase II field test findings in which patients ranked fatigue as their most distressing and disruptive symptom.

In the MSQLI, fatigue is assessed with a modified form of the Fatigue Impact Scale (FIS) (Fisk, Ritvo and Archibald, 1991), based on items derived from interviews with MS patients about how fatigue impacts their lives. This instrument provides an assessment of fatigue effects in terms of physical, cognitive, and psychosocial functioning. Prior to selection for the MSQLI, the full scale FIS was evaluated with MS patients, Chronic Fatigue Syndrome patients and individuals diagnosed with essential hypertension. Findings demonstrated high internal consistency for the whole scale and within each dimension, as well as the scale's capacity to discriminate fatigue effects in MS patients from those experienced by patients with chronic fatigue and essential hypertension (Fisk, Ritvo, Archibald, Murray, Field and Blanchard, 1992).

The FIS was abbreviated during Phase II by eliminating items which appeared *both* content-redundant *and* had high inter-item correlations. The current MSQLI version consists of 21 items and is referred to as the Modified Fatigue Impact Scale. A 5 item version of the MFIS is also available if time is limited but investigators are urged to use the 21 item version whenever possible since it provides a breakdown into subscales.

c)   **MOS Pain Effects Scale (PES)**

More than half of clinic attending MS patients in two studies reported a high prevalence of chronic pain (Moulin, Foley and Ebers, 1988; Archibald, Ritvo, Fisk, Murray and McGrath, 1991). In the second study, 85 clinic-attending MS patients were assessed with the Pain and Disturbing Sensation Inventory, a structured interview instrument. Results indicated 53% of clinic-attending patients reported severe levels of pain and disturbing body sensations during a majority of waking hours. (Archibald, Ritvo, Fisk, Murray and McGrath, 1991). This study also showed that MS patients affected by pain and disturbing sensations had lower Mental Health Inventory scores than patients who reported no pain ($p<.05$), despite the comparability of the pain/no pain groups in neurological impairment, symptom duration and age. Such findings suggest that pain is also a significant factor in the mental health and management of MS patients.

A number of different scales assessing pain and disturbing sensations were evaluated during the field test, including one based solely on interviews with MS patients. The scale with the best psychometric performance was derived from the pain scale contained in the Medical Outcomes Study Functioning and Well-Being Profile, a 149 item health status questionnaire used in the Medical Outcomes Study. Based on Phase II results, the scale was reduced to 6 items assessing the degree to which pain and unpleasant sensations interfere with mood, ability to walk or move, sleep, work, recreation and enjoyment of life. This 6 item scale is called the MOS Pain Effects Scale.

d)   **Sexual Satisfaction Scale (SSS)**

Changes in sexual functioning are commonly reported by individuals with MS (Valleroy and Kraft, 1984) with any phase of the sexual response affected. This can be the direct result of lesions in the spinal cord or brain, or an indirect effect of physical symptoms that interfere with sexual activity, or of emotional distress that impairs sexual desire or other aspects of the sexual response (Kalb, LaRocca, and Kaplan, 1987). Because self-report and interviewer-administered

measures developed to study sexual dysfunction in other populations were too lengthy, items from the Sexual History Form (Nowinski and LoPiccolo, 1979) were selected to provide an indicator of overall sexual adjustment. This resulted in a 4 item scale addressing the degree of satisfaction experienced with: physically expressed affection; the variety of sexual activities engaged in; and with the sexual relationship generally. A final item addresses the perceived satisfaction experienced by the partner within the relationship..

e)   Bladder Control Scale (BLCS) and Bowel Control Scale (BWCS)

Bladder and bowel dysfunction are among the most troubling problems associated with MS disease (Kraft, et al., 1984). In the Phase II field test, bladder and bowel problems were ranked as one of the three most distressing and disruptive symptoms by patients (N = 300). Available symptom management methods can either be ineffective or unacceptable and the social stigma sometimes associated with these dysfunctions is often distressing (Scheinberg and Holland, 1987).

The MSQLI Bladder Control Scale and Bowel Control scale were based on the items derived from the Bowel-Bladder Function Scale (Turnbull, Hoare, Ritvo, Fisk and Murray, 1992) and the Sickness Impact Profile. Items were added during the Phase I review and psychometrically evaluated in Phase II. There are now 4 items to evaluate bladder control and 5 for bowel control and their impact on lifestyle. These two scales are separately.

f)   Impact of Visual Impairment Scale (IVIS)

The 5 item Impact of Visual Impairment Scale was based on items derived from the Functional Capacities Assessment developed by the Michigan Commission for the Blind. They refer focally to the difficulties patients have with simple visual recognition tasks such as reading that cannot be corrected by glasses or other visual aids.

g)   Perceived Deficits Questionnaire (PDQ)

Cognitive impairment is a common and disabling MS consequence. Cognitively-impaired MS patients are less likely to work and socialize, and are more likely to need personal assistance than cognitively-intact MS patients with a comparable physical disability (Rao, Leo, Ellington, Nauertz, Bernardin, and Unverzagt, 1991). A study by Fischer (1993) further suggests that MS patients' perceptions of their memory powerfully impact functional status: patients whose objective memory performance was intact, but who perceived their memory as impaired, were as likely to be unemployed as patients with actual memory deficits.

In the MSQLI, the subjective self report of cognitive function is captured in the 20 item Perceived Deficits Questionnaire (Sullivan, Edgley, and Dehoux, 1990). This measure has the advantage of being broader in scope than other current subjective measures and was designed specifically for use with MS patients. It covers the domains of cognitive function most often impaired in MS: attention; retrospective memory; prospective memory; and planning and

organization. A 5 item version of the PDQ is also available if time is limited but investigators are urged to use the 20 item version whenever possible since it provides a breakdown into subscales.

h)   Mental Health Inventory (MHI)

In a recent study of persons with MS (Ritvo, Fisk, Archibald, Murray and Field, 1996) the mean Mental Health Inventory score for 130 clinic-attending MS patients was found to be at the lowest 25th percentile of the normative population assessed during the National Health Insurance Study sample (Veit and Ware, 1983). Altogether, 45.3 per cent of MS patients in this study had scores that fell within the lowest quartile of mental health status relative to the normative sample. This study suggests that the emotional/mental health status of persons with MS patients needs to be a major concern in health service delivery.

From all available measures the Mental Health Inventory was selected for inclusion in the MSQLI. The Mental Health Inventory was the primary mental health scale developed during the National Health Insurance Study (Veit and Ware, 1983) and its current form has been refined through extensive studies of reliability, validity, and factor structure. During the National Health Insurance Study, the Mental Health Inventory was administered to over 5000 subjects in a stratified sample from six US cites, over of a three to five year period. The MHI has been found to be reliable and to correlate highly with several other mental health assessment instruments (Sherbourne, Hays, Ordway, DiMatteo and Kravitz, 1992; Veit and Ware, 1983),

Depending on the purpose of assessment, an investigator or clinician may choose to use a reduced 18 item version that is highly correlated with the original scale, or a brief 5 item version which is also highly correlated. but less sensitive to changes in distress and well-being. The 18 item version is suggested for the MSQLI.

i)   MOS Modified Social Support Survey (MSSS)

A large body of literature indicates that social interaction is an important construct in understanding individual well-being. Increasing evidence suggests people with chronic illnesses have limited access to social supports due to disease consequences (Heitzmann and Kaplan, 1988). These limitations negatively impact psychosocial functioning and disease management (Kaplan and Toshima, 1990). Social support can thus affect both emotional and physical health outcomes (Heitzmann and Kaplan, 1988; Kaplan and Toshima, 1990; Tilden, 1985).

In addition to SF 36 subscales which address social functioning and its impairments, the MOS Social Support Survey, a brief multidimensional self administered instrument, was selected to assess perceived support. The MOS-SSS was developed in the Medical Outcomes Study, a longitudinal study of patients with prevalent chronic illnesses. The original 19 items were factor analyzed, using responses from 2987 patient-subjects and four dimensions of social support were discriminated: 1) emotional informational support; 2) tangible support (the provision of material aid or behavioral assistance); 3) positive social interaction (the availability of other persons to do fun things with you); and 4) affectionate support. Subsequent analyses with different populations have,

however, indicated relatively high internal consistency estimates for all scale items (C. Sherbourne, 1996, Personal Communication). For the MSQLI, 18 items were selected based on their psychometric field test performance and these constitute the MOS Modified Social Support Survey. A 5 item version of the MSSS is also available if time is limited but investigators are urged to use the 18 item version whenever possible since it provides a breakdown into subscales.

4.   Utilization of Data Analyses in Item-Scale Reduction

As described previously, an important goal of the Phase II field test was to undertake a 25% reduction in items, making the instrument applicable to clinical trials and activities. Such applications, in turn, will yield better understandings of its responsiveness to change.

The item reduction process was initially guided by specific criteria for differentiating 'outcome' variables from mediating or moderating 'process' variables. Item reduction was further guided by an observed *consistency* between the theoretically-based item intent and the patient's ability to respond accordingly. Consistency was assessed statistically in terms of 'internal consistency' estimates which identified items that did not perform as predicted or intended. Once identified, it was possible to review whether a particular item was inadequately constructed for sampling purposes, sampling at a level too specific or general for the purpose intended.

These discriminations were a natural challenge to be increasingly clear about the core defining content of each scale. The content that most articulately described the health concept, addressing it in sufficient (but not overly extensive) detail so as to capture meaningful variance in the experience of patients was reliably identified as the defining core.

Specific decisions regarding item deletion can illustrate the process undertaken. For example, in the Impact of Visual Impairment Scale we dropped several items related to the use of visual aids. Because they were dichotomous, they served only to indicate the presence of absence of extreme visual impairment. The items retained more directly referred to visual recognition difficulties which were more common and, in turn, yielded a more variable set of responses from patients. On the other hand, these items also assessed the presence or absence of extreme visual disability.

In the Bowel Scale, we deleted several items related to the methods used to assist adequate bowel functioning. Once again, this section only sampled extremes of dysfunction, which were adequately measured in other retained items describing the level and type of dysfunction experienced.

Another significant reduction involved the Sexual Functioning Scale where we ultimately opted for summary items relating to satisfaction, in contrast to more detailed inquiries. Our experience with missing data in this section indicated that patients were not prepared to respond to such detailed, explicit queries in a self report format. On the other hand, the more general questions effectively evaluated significant differences in sexual activity and function without the need for such specific detail.

Other item reductions were more subtle than those described above. We deliberately chose to compare the SIP vs. the SF 36 to assess the relative variance accounted for by these generic HQL measures. Although the SIP accounted for a modest degree of additional variance, its length (136 items) did not justify this additional proportion. Thus, given its relative brevity and its measurement properties, we opted to use the SF-36 rather than the SIP. Similarly, we evaluated two pain scales, one developed specifically for an MS population and one developed for generic purposes. Although the two scales were largely comparable, the generic scale slightly outperformed the MS specific scale. Consequently, we opted to retain that scale and delete the other.

We also evaluated two social functioning scales, the MOSSS and the UCLA Loneliness-Companionship scale. The MOSSS was a slightly better performer in statistical terms, and had the added advantage of providing comparisons between MS patients and other chronic disease groups which had been previously tested. Consequently we opted for retaining only the MOSSS.

The final deletions were related to defining satisfaction with care as a process rather than outcome variable (i.e. we deleted that scale from the inventory) and to deleting several fatigue items that were suggested for the purpose of discriminating activity- related fatigue vs. endogenous fatigue. Although we see such discriminations as important, they are more readily obtained in a full clinical interview. In a self report format, , they seemed to be too confusing to patients.

On a final note regarding deletion, we must point out that although we included a brief neuropsychological battery in the Phase II project, the battery was never considered part of the MSQLI. These assessments are considered 'objective' rather than self report measures. They also require skilled technicians, not readily available in settings where self report instruments are used. Furthermore, the selection of neuropsychological measures may substantially vary in accord with the purpose of the clinical or treatment trial conducted. As such, we decided to leave these measures to discretion of the researcher/clinician. We have confidence in the neuropsychological battery administered in the field test, but we see it as only one of several high quality batteries that could be used.

Table 1
Expert Panel Responses To Core Inventory Candidate Measures

Domain	Allied Health Professional Panel % approval	Neurologist Panel % approval	Consumer Panel % approval
Objective Physical Measures			
Questions**	86%	75%	84%
Instructions**	86%	100%	87%
Objective Cognitive Measures			
Questions	86%	100%	84%
Instructions	86%	100%	84%
Patient Profile			
Questions	86%	100%	100%
Instructions	86%	100%	100%
Caregiving			
Questions**	72%	100%	84%
Instructions	86%	100%	84%
Transportation			
Questions	86%	100%	84%
Instructions	100%	100%	84%
Fatigue			
Questions	100%	100%	84%
Instructions	100%	100%	84%

** = additional items written until 80 % agreement regarding content validity was achieved

Table 1
Expert Panel Responses To Core Inventory Candidate Measures - Continued

Domain	Allied Health Professional Panel % approval	Neurologist Panel % approval	Consumer Panel % approval
Perception of Cognitive Function			
Questions	86%	100%	84%
Instructions	100%	100%	84%
Bowel and Bladder			
Questions**	86%	100%	50%
Instructions	86%	100%	67%
Pain/Sensory			
Questions	100%	100%	100%
Instructions	86%	100%	100%
Impact of Illness			
Questions	100%	100%	84%
Instructions	86%	100%	84%
Emotional Status			
Questions	100%	100%	100%
Instructions	100%	100%	100%
Social Relations			
Questions	100%	100%	100%
Instructions	100%	100%	100%

** = additional items written

5.   Comparison of the MSQLI with Similar Measures

The development of the MSQLI coincided with that of two other MS quality-of-life profile measures: the MS Quality of Life (MSQOL-54) instrument developed by Vickrey and colleagues (Vickrey, Hays, Narooni, Myers, & Ellison, 1995) and the Functional Assessment of Multiple Sclerosis (FAMS) quality-of-life instrument developed by Cella and colleagues (Cella, Dineen, Arnason, Reder, Webster, Karabatsos, Chang, Lloyd, Mo, Stewart, & Stefoski, 1995). The MSQLI, MSQOL-54, and FAMS have several similarities. First, each combined generic and disease-specific assessment, resulting in some content overlap (see Table 2). Second, input from MS experts was obtained in their development. Patient input was also obtained for the MSQLI and FAMS, however the MSQLI was the only instrument which incorporated caregiver input, particularly useful in understanding patients whose self report is hindered by disease effects (e.g. patients with cognitive deficits). Third, each of the three instruments has undergone reliability and construct validity testing.

Several key differences also exist in the development and composition of these instruments. Although all three inventories include a generic HRQL measure, the methods for selecting this measure differed. Cella et al. and Vickrey et al. selected their generic measures *a priori*. In contrast, two widely-used generic HRQL measures (the SF-36 and the Sickness Impact Profile) were field-tested to determine, empirically, their applicability in developing the MSQLI. Both performed comparably in terms of subscale reliability, with the SF-36 retained because of its brevity. Vickrey and colleagues also used the SF-36 as their core generic HRQL measure, while Cella and colleagues chose the Functional Assessment of Cancer Therapy scale (FACT-G; Cella, Tulsky, Gray, et al., 1993), a measure not widely applied outside the assessment of cancer patients.

Second, most of the disease-specific measures included in the MSQLI are established scales. In contrast, the MSQOL-54 and FAMS were formed by adding individual items to generic measures. One consequence of the latter approach is that symptom clusters, usually evaluated separately, were sometimes combined into a single scale (e.g., the FAMS Thinking/Fatigue scale). Moreover, the use of pre-existing symptom-related scales, in the MSQLI, has the advantage of permitting comparisons of specific symptoms across subject samples, both historically (i.e., with previous studies using these instruments) and concurrently (i.e., within a study).

A third and critical difference between the instruments was the method by which they were tested for reliabilty and validity. The MSQLI was tested on consecutive clinic-attending samples carefully recruited to represent the *full* range of low, moderate and high levels of neurological disability typically seen in the MS population, as well as the typical ratios of female to male patients (2:1). The levels of disability were based on EDSS scores assessed by clinic neurologists, as is standard in clinical trials. In contrast, the MSQOL-54 was tested on a sample of consecutive clinic attenders which did not necessarily represent the full disability range nor gender ratio of the MS population. Most importantly, rather than physician-assessed EDSS, the sample was characterized by EDSS scores derived from patients, themselves. This approach compromises analyses of reliability-validity due to the confounding of patient-reported HRQL with patient-reported EDSS. Because the EDSS is supposed to be an independent (i.e. objective) criterion against which HRQL

scores are compared, deriving it from patient self report is less than optimal. To accept the patients' report of EDSS as an objective measure, one must assume that patients reliably reported their current EDSS scores. This is a difficult assumption as patients whose quality of life is lower have been known to assess their neurological disability as higher.

The FAMS field test was also somewhat less than ideal in that the validation sample consisted of 377 subjects surveyed by mail, supplemented by a clinically assessed cohort of 56 subjects. The subjects for both cohorts represented a convenience sample that was not stratified to reflect either disability levels or gender distributions within the MS population. In addition, the EDSS scores for the mailed cohort were not clinically derived (i.e. by neurologists) but were again based on patient self report, introducing the same problems as described above.

A fourth important difference was related to the manner in which tests were administered. All MSQLI field test participants completed the instrument in the clinic, with a trained interviewer available to assist when necessary. In addition to undergoing a neurologic exam, MSQLI field test subjects also underwent objective, quantitative assessment of upper-extremity function, lower-extremity function, and neuropsychological function as part of the validation study. In contrast, the MSQOL-54 and FAMS were *mailed* to patients, who completed them at home, in conditions uncontrolled with respect to assistance from friends and family members. Only a small number of patients in the FAMS study ($n = 56$) completed the instrument in the clinic under controlled conditions and were examined neurologically at the time of the validation study. Furthermore, no quantitative measures of physical or cognitive function were administered to these patients. In summary, the MSQLI was administered in a more standardized manner, and the MSQLI validation sample can be more thoroughly characterized, especially in reference to criterion ("known groups") validity.

Lastly, the sampling plan for the MSQLI field test ensured broad representation in terms of geographic location (Cleveland, Halifax, New York, and Toronto) whereas patients in the MSQOL-54 and FAMS samples were clinic attenders from a single U.S. city (Los Angeles and Chicago, respectively). Thus, the applicability of the MSQLI to the MS population as a whole, regardless of geopgraphic location, has been more adequately established.

6.   How to Use the MSQLI

How should the MSQLI be used? We strongly recommend the instrument be used in its entirety. As noted earlier, we have presented somewhat abbreviated 5 item versions of four symptom-specific instruments for MS investigators and clinicians to use when brevity is a major concern. However, we caution that important opportunities for comparison of specific symptoms with results of other MS studies and results of studies with other chronically-ill populations may be lost when the abbreviated measures are used. We are confident of the ability of the MSQLI to discriminate among groups of MS patients with different symptom patterns and levels of disability and would encourage the use of the MSQLI in cross-sectional studies. In addition, we are optimistic about the MSQLI being able to detect functional changes perceived as important by MS patients. However, we must caution that neither we nor other investigators (Cella et al., 1995; Vickrey et al.,

1995) have yet documented the sensitivity of these instruments to change over time in MS patients. For this, we must await the completion of longitudinal studies incorporating the MSQLI. As such, we encourage other investigators to extend our work on the MSQLI.

7.   A Note on the Reliabilities of the MSQLI Scales

This user's manual has been designed to provide, as concisely as possible, all the information necessary for investigators to effectively utilize the MSQLI. To this end, the text has not been burdened with a technical discussion of the extensive statistical analyses that were undertaken as part of the field testing of the MSQLI. However, users of the MSQLI may be interested in knowing the reliabilities of the instruments making up the MSQLI before deciding to use these scales. Tables 3 and 4 summarize the reliability analyses performed on the component scales of the MSQLI. The next two paragraphs provide an explanation of the methods used to assess reliability of the MSQLI scale. Although these two paragraphs are somewhat technical in nature, they provide some insight into the interpretation of Tables 3 and 4.

In the present study, we utilized the linear composite model of scale construction in which diverse but related items rated on an ordinal scale are summed to arrive at a total score which approximates the characteristics of an equal interval scale. The most common method for evaluating reliability for such scales is Cronbach's alpha, sometimes referred to as a coefficient of internal consistency. Scale scores are conceptualized as being composed of two components: true variance and error variance. Reliability may be thought of as a way of estimating the proportion of true variance in a score. In this model, Cronbach's alpha is considered to be a lower-bounds estimate of reliability, i.e., the "true" reliability of the scale may be higher than alpha indicates but cannot be lower. Since true variance is by definition reproducible, the terms reliability and reproducibility are sometimes used interchangeably. However, reliability is sometimes confused with reproducibility in the concrete sense of the term, i.e., do subjects given a scale on Monday and Friday get the same scores? This way of assessing reliability is termed test-retest reliability. Like alpha, test-retest reliability is a lower-bounds estimate of the proportion of true variance in a score. However, test-retest reliability makes no provision for the fact that the function being measured may itself change in between testings.

There are many ways to interpret Cronbach's alpha. As a measure of internal consistency, it tells us the extent to which the individual items in the scale are all "pulling in the same direction," i.e., probably measuring the same thing. Adding together 10 items that are unrelated to one another and that measure different things would result in a low alpha and would be a meaningless scale. The old adage about not adding together apples and oranges applies perfectly here. How high should alpha be? There is no simple answer to that question. However, it is clear that if alpha is 50 the scale is probably not useful since half of the variation in the score is error. In the present study, it was decided in advance to utilize some general guidelines. Scales with an alpha of .70 or better would be considered adequate for inclusion. Scales with an alpha between .50 and .70 would be considered for deletion or revision to improve reliability. Scales with an alpha below .50 would generally not be retained. Of course our goal would be to achieve alphas higher than .70. However, when using scales for analysis of group trends, moderate reliabilities are considered adequate.

Table 2
Comparison of Content of MS-Specific Quality of Life Instruments

Scale	MSQLI[1]	MSQOL-54[2]	FAMS[3]
Generic quality of life	SF-36 (36 items)*	SF-36 (36 items)*	FACT-G[4] (28 items)
Fatigue	Modified Fatigue Impact Scale (21 items)*	Energy (5 items)	5 selected items from the 9-item Thinking and Fatigue Scale
Pain	MOS Pain Effects Scale (6 items)	Pain (3 items)	4 selected items from the 7-item Physical Symptom Scale
Sexual function/ satisfaction	Sexual Satisfaction Scale (4 items)	Sexual Function (5 items)	1 selected item from the 15 item Additional Concerns Scale
Bladder control	Bladder Control Scale (4 items)	1 selected bowel/bladder item from the Social Function scale	2 selected items from the 15 item Additional Concerns Scale
Bowel control	Bowel Control Scale (5 items)	1 selected bowel/bladder item from the Social Function scale	None
Visual function	Impact of Visual Impairment Scale (5 items)	None	None
Cognitive function	Perceived Deficits Questionnaire (20 items)	Cognitive Function (4 items)	4 selected items from the 9-item Thinking and Fatigue scale
Emotional status	Mental Health Inventory (18 items)*	Mental Health Inventory (5 items); Health Distress (4 items)	Emotional Well-Being (7 items) General Contentment (7 items) 3 selected items from the 15 item Additional Concerns Scale
Social relationships and support	Modified Social Support Scale (18 items)*	Social Function (3 items)	Family/Social Well-Being (7 items)

[1]MS Quality of Life Inventory
[2]MS Quality of Life (MSQOL-54) instrument
[3]Functional Assessment of Multiple Sclerosis
[4]Functional Assessment of Cancer Therapy-General
*Indicates that these measures also have subscales with acceptable reliability.

Table 3
Reliabilities of SF-36 Scales

Scale	Range	Mean	Standard Deviation	Number of Items	Alpha
Physical Functioning	0-100	38.3	29.9	10	.94
Role-Physical	0-100	32.2	36.3	4	.80
Bodily Pain	0-100	64.8	27.3	2	.91
General Health	0-100	55.7	22.1	5	.77
Vitality	0-90	40.7	21.5	4	.85
Social Functioning	12.5-100	63.6	25.1	2	.67
Role-Emotional	0-100	62.2	38.8	3	.75
Mental Health	0-100	67.9	19.3	5	.82
Physical Component Summary Score	13.6-61.9	34.7	10.4	35	*
Mental Component Summary Score	15.6-70.0	47.9	11.6	35	*

*The **PCS** and **MCS** are not simple linear composite scales but rather are factor scales derived from a Principal Components analysis. A straightforward application of Cronbach's alpha to such scales is not appropriate. Ware et al. (1995) reported reliabilities of .92 and .91 respectively for these scales based on a sample of 1,440 outpatients drawn from the Medical Outcomes Study.

Table 4
Reliabilities of MS-Specific Quality of Life Scales

Scale Name	Subscale	Number of Items	Alpha
Modified Fatigue Impact Scale	**Cognitive**	10	.95
	Physical	11	.91
	Psychosocial	2	.81
	Total	21	.81
	Abbreviated Version	5	.80
MOS Pain Effects Scale	**Total**	6	.86
Sexual Satisfaction Scale	**Total**	4	.91
Bladder Control Scale	**Total**	4	.82
Bowel Control Scale	**Total**	5	.78
Impact of Visual Impairment Scale	**Total**	5	.86
Perceived Deficits Questionnaire	**Attention**	5	.82
	Retrospective Memory	5	.86
	Prospective Memory	5	.74
	Planning/Organization	5	.85
	Total	20	.93
	Abbreviated Version	5	.84
Mental Health Inventory	**Anxiety**	5	.80
	Depression	5	.87
	Behav. & Emot. Control	4	.78
	Positive Affect	4	.83
	Total	18	.93
	Abbreviated Version	5	.82
MOS Modified Social Support Survey	**Tangible Support**	4	.87
	Emotional Support	8	.95
	Affective Support	3	.91
	Positive Support	3	.92
	Total	18	.97
	Abbreviated Version	5	.88

Administration and Scoring

1.   **List of Instruments Making up the MSQLI (in order of administration)**

        Health Status Questionnaire (SF-36) - 36 items
        Modified Fatigue Impact Scale (MFIS) - 21 items*
        MOS Pain Effects Scale (PES) - 6 items
        Sexual Satisfaction Scale (SSS) - 5 items
        Bladder Control Scale (BLCS) - 4 items
        Bowel Control Scale (BWCS) - 5 items
        Impact of Visual Impairment Scale (IVIS) - 5 items
        Perceived Deficits Questionnaire (PDQ) - 20 items*
        Mental Health Inventory (MHI) - 18 items*
        MOS Modified Social Support Survey (MSSS) - 18 items*

        *(Abbreviated 5 item versions of these scales are also available)

2.   **General Instructions Regarding Administration**

The MSQLI systematically assesses *current* health status from the patient's perspective. In the field test, patients were asked to respond based on their functioning *during the previous 4 weeks*, a time frame that can be modified for other applications. The standard version of the MSQLI is designed to be self-administered by most patients in approximately **45** minutes. While abbreviated versions of four of the MSQLI scales are available which reduce administration time to **30** minutes, use of the full-length MSQLI is strongly encouraged. The MSQLI is intended to supplement but not replace objective measures of physical and cognitive function (e.g., EDSS, quantitative measures of upper and lower extremity function, magnetic resonance imaging, and objective measures of memory and concentration). Also, the MSQLI itself does not cover demographic and medical background information, since many investigators are already collecting this information. Those investigators and clinicians who are looking for systematic ways of collecting these data may want to refer to the Demographic Questionnaire and Health Background Questionnaire in the MSQLI-Field Test Version which is available from the NMSS by calling Dr. Nicholas LaRocca at (212) 476-0414.

The MSQLI is intended to be broadly applicable to all MS patients who can comprehend its instructions and questions, regardless of their level of physical impairment. Under optimal conditions, patients come to a clinic or office and complete the MSQLI independently, with no other person present but with a trained interviewer available to answer any questions that might arise. This approach helps to ensure that responses are indeed coming from the patient (not a family member or friend) and that data are as complete as possible. The MSQLI forms should then be reviewed to ensure that the patient has provided one response for each question. In some circumstances, however, this form of administration may not be practical. In such instances, patients who can complete questionnaires on their own may be given the MSQLI to fill out at home.

Whether completed in the investigator's office or at home, patients should be instructed to mark their responses clearly (usually by circling the appropriate number) and to choose only one response for each item. If a patient has marked two responses for the same item, the patient should be asked to decide which is the *best* response for that item. If the patient is not available when multiple responses are detected, the investigator or clinician should develop a systematic method for selecting which response to score.

Administration of the MSQLI can also be adapted for patients whose MS symptoms limit their ability to complete questionnaires independently. For patients whose visual problems prevent them from reading, the MSQLI should be entirely interview-administered: each item, along with the appropriate response choices, should be read to the patient and his/her response to that item recorded by the interviewer. (This may require some minor wording adaptations, substituting "like" or "such as" for "e.g.", "I" for "the interviewer", etc.) Patients whose sensory or motor problems prevent them from marking their own responses should be given a blank copy of the MSQLI to read, and the instructions should be modified to direct the patient to tell the interviewer the *number* of the appropriate response for each question. (Sample modified instructions are provided for each scale.) After reading the modified instructions, the interviewer should read the first question in its entirety and prompt the patient for the number of the appropriate response. For subsequent single-item questions, the interviewer can simply prompt the patient with the question number. For multiple-item questions that share a single stem, the interviewer should read the question stem and the first item after the stem, and then prompt the patient with the letter or number corresponding to subsequent items (e.g., "b?"). If subsequent items continue onto a new page or if administration of the MSQLI is interrupted in the midst of a multiple-item question, the interviewer should repeat the stem and the next item, and then resume prompting the patient with the letter or number corresponding to subsequent items.

Following administration of the MSQLI, the interviewer does a brief review of the forms for clarity and completeness while the patient is still present. Later, after the patient has left, the answers to each item are entered into the investigators computer system for analysis and interpretation. The next section provides detailed instructions for administering each scale to patients and for scoring each scale once data has been entered into a computer. The net result of scoring the MSQLI is a series of scores, each of which represents a different facet of quality of life. The MSQLI does not provide a single, overall number summarizing quality of life. However, for those investigators who are interested in more global measures, the next section, the Health Status Questionnaire, provides instructions for calculating a *physical component summary scale* score and a *mental component summary scale* score using the items on the SF-36.

3. Generic Quality of Life Measure: Health Status Questionnaire (SF-36)

a) Background

The Health Status Questionnaire (SF-36) is a one of the most widely-accepted generic health status measures. It is a brief (36-item) scale developed by Stewart, Hayes and Ware (1988) from items included in the Medical Outcomes Study. Briefer versions (e.g., SF-20) have also been

developed, but given their psychometric limitations, use of the full SF-36 is strongly encouraged. (Investigators and clinicians interested in these short forms are referred to Stewart and Ware (1992).) Manuals describing administration and scoring of this measure are available through the Health Institute's Order Fulfillment Department, New England Medical Center, PO Box 9179, Boston, MA 02118 (Phone: (800) 572-9394).

b)   Administration

The response format and order of administration of some items was modified for the MSQLI based on the results of pilot testing prior to the field test. Most questions are self-explanatory, although the following clarifications may be useful.

Question 1:   This refers to a patient's health in general, *including his/her MS as well as any other illnesses or non-MS symptoms*. The definition of "health" should be left up to the patient, and may include mental as well as physical health. If the patient asks for a time frame, tell him/her "during the past 4 weeks." Otherwise, do not give a time frame for this item.

Question 2:   The definition of "getting sick" should be left up to the patient. Some patients may think of their susceptibility to flu, colds, and other viral infections, whereas others may define this in terms of their susceptibility to more serious or chronic illnesses.

Question 4:   This question asks the patient to think about their activities "on a typical day". Note that, unlike some of the other questions, a *larger* number means that the patient is *less* limited in those activities. The examples of vigorous and moderate activities are given to help define the intensity of these activities; the patient does not need to think of whether his/her health limits his/her ability to perform each of these activities, but rather, should respond in terms of whether his/her health limits *these types of activities in general*. If the patient asks for a specific time frame, tell him/her to "think of a typical day during the past 4 weeks". For item "j", "3" should be selected only if the patient is completely independent in bathing and dressing.

Question 6:   This question refers to pain from any source (including MS) and includes headaches. The patient's response should provide an overall rating of his/her pain, taking into account both frequency and severity of this pain.

Question 7:   This question refers to work either outside or inside the home, but *not* to personal care.

Question 9:   Patients may vary greatly in the types of social activities they do and the amount of time they spend doing them. This question asks the patient to use his/her normal social activities as a baseline, which includes any interactions with others either in person, by phone, or in writing.

Question 10:   For "b", "very nervous" means very anxious, worried or tense. For "e", the patient should define "energy", which can include physical energy, mental energy, or both. For "f", "downhearted and blue" means unhappy or depressed. If the patient asks about the meaning of the word "visiting" in item "j", tell him/her that this can refer to visiting in person or by phone.

c)   **Scoring (Standard 36-item version)**

The SF-36 has a single item covering change in health status over the last year and 8 multi-item scales. Two summary scales (Physical and Mental) have also been derived using factor analytic methods. Scales are set up so that a higher score indicates better health. To achieve this, responses on 10 items are recoded before being added to other items on the same scale. Raw scale scores are then transformed to a 0-100 scale.

Health Transition Item:
This single item (Item #3) is scored as indicated on the response form (i.e., no conversion is necessary). Thus, it ranges from 1-5.

Physical Functioning Scale (PF):
Compute raw score as follows: 4a+4b+4c+4d+4e+4f+4g+4h+4i+4j
Raw scores on this scale range from 10-30.
Compute transformed score as follows: [(Raw score-10)/20] x 100

Role-Physical Scale (RP):
Compute raw score as follows: 5a+5b+5c+5d
Raw scores on this scale range from 4-8.
Compute transformed score as follows: [(Raw score-4)/4] x 100

Bodily Pain Scale (BP):
Assign raw scores for Item #6 responses as follows:

None(1) =	6.0
Very mild (2) =	5.4
Mild(3) =	4.2
Moderate(4) =	3.1
Severe(5) =	2.2
Very severe(6) =	1.0

Assign raw scores Item #7 responses as follows:
Not at all(1) = 6 if Item #6 response was None(1) or if Item #6 was not answered *or*
        5 if Item #6 response was *not* None(1)
A little bit(2) = 4 if Item #6 was answered
        (or 4.75 if Item #6 was not answered)
Moderately(3) = 3 if Item #6 was answered
        (or 3.5 if Item #6 was not answered)

Quite a bit(4) =   2 if Item #6 was answered
                         (or 2.25 if Item #6 was not answered)
Extremely(5) =   1

Compute raw score by adding assigned raw scores for Items 6 and 7.
Raw scores on this scale range from 2-12.
Compute transformed score as follows: [(Raw score-2)/10] x 100

General Health Scale (GH):
       Assign raw scores to Item #1 responses as follows:
           Excellent(1) = 5.0
           Very good(2) =   4.4
           Good(3) =   3.4
           Fair(4) =   2.0
           Poor(5) =   1.0
       Assign raw scores to Item #2b and d responses as follows:
           Definitely true(1) =   5
           Mostly true(2) =   4
           Not sure(3) =   3
           Mostly false(4) =   2
           Definitely false(5) =   1
       No conversion is necessary for scores on Items #2a and c.

Compute raw score by adding scores for: 1+2a+2b+2c+2d.
Raw scores on this scale range from 5-25.
Compute transformed score as follows: [(Raw score-5)/20] x 100

Vitality Scale (VT):
       Assign raw scores to Items #10a and e responses as follows:
           All of the time(1) =   6
           Most of the time(2) =   5
           A good bit of the time(3) =   4
           Some of the time(4) =   3
           A little of the time(5) =   2
           None of the time(6) =   1
       No conversion is necessary for Items #10g and I.

Compute raw score by adding scores for: 10a+10e+10g+10i.
Raw scores on this scale range from 4-24.
Compute transformed score as follows: [(Raw score-4)/20] x 100

Social Functioning Scale (SF):
       Assign raw scores to Item #9 responses as follows:
           Not at all(1) =   5

```
Slightly(2) =          4
Moderately(3) =        3
Quite a bit(4) =       2
Extremely(5) =         1
```
No conversion is needed for scores on Item 11.

Compute raw score by adding scores for Items 9 and 11.
Raw scores on this scale range from 2-10.
Compute transformed score as follows: [(Raw score-2)/8] x 100

Role-Emotional Scale (RE):
Compute raw score by adding the following scores: 8a+8b+8c.
Raw scores on this scale range from 3-6.
Compute transformed score as follows: [(Raw score-3)/3] x 100

Mental Health Scale (MH):
Assign raw scores to Item #10d and h as follows:
```
All of the time(1) =               6
Most of the time(2) =              5
A good bit of the time(3) =        4
Some of the time(4) =              3
A little of the time(5) =          2
None of the time(6) =              1
```
No conversion is needed for Item #10b, c, and f.

Compute raw score by adding the following: 10b+10c+10d+10f+10h.
Raw scores on this scale range from 5-30.
Compute transformed score as follows: [(Raw score-5)/25] x 100

Physical Components Summary Scale (PCS):
Scoring of the PCS involves 3 steps:
1)   Standardization of the 8 SF-36 scales (based on means and standard deviations for the US population);
2)   Weighting and aggregation of the 8 SF-36 scales; and
3)   Transformation of the aggregate scale score to a T-score.

Z-score standardizations (Step 1) are done as follows:

$PF\_Z = (PF-84.52404)/22.89490$

$RP\_Z = (RP - 81.19907)/33.79729$

$BP\_Z = (BP - 75.49196)/23.55879$

$GH\_Z = (GH - 72.21316)/20.16964$

$VT\_Z = (VT - 61.05453)/20.86942$

SF_Z = (SF - 83.59753)/22.37642

RE_Z = (RE - 81.29467)/33.02717

MH_Z = (MH - 74.84212)/18.01189

Z-scores are then aggregated as follows for the PCS:

$$AGG\_PHYS = (PF\_Z * 0.42402) + (RP\_Z * 0.35119) + (BP\_Z * 0.31754) +$$

$$(GH\_Z * 0.24954) + (VT\_Z * 0.02877) + (SF\_Z * -0.00753) +$$

$$(RE\_Z * -0.19206) + (MH\_Z * -0.22069)$$

Finally, the aggregate Physical Components score is transformed to a T-score using the following formula:

$$PCS = 50 + (AGG\_PHYS * 10)$$

Mental Component Summary Scale (MCS):
Scoring of the MCS involves 3 steps:

1) Standardization of the 8 SF-36 scales (based on means and standard deviations for the US population);
2) Weighting and aggregation of the 8 SF-36 scales; and
3) Transformation of the aggregate scale score to a T-score.

Z-score standardizations (Step 1) are done as for the Physical Components Summary Score (see above).

Z-scores are then aggregated for the MCS as follows:

$$AGG\_MENT = (PF\_Z * -0.22999) + (RP\_Z * -0.12329) + (BP\_Z * -0.09731) +$$

$$(GH\_Z * -0.01571) + (VT\_Z * 0.23534) + (SF\_Z * 0.26876) +$$

$$(RE\_Z * 0.43407) + (MH\_Z * 0.48581)$$

Finally, the aggregate Mental Components score is transformed to a T-score using the following formula:

$$MCS = 50 + (AGG\_MENT * 10)$$

4. Modified Fatigue Impact Scale (MFIS)

a) Background and Administration

Fatigue is an extremely common, but under-recognized, symptom in MS. In fact, 84.0% of the MSQLI Field Test sample reported fatigue as a current MS symptom. The MSQLI Modified Fatigue Impact Scale (MFIS) consists of 21 items selected from the Fatigue Impact Scale (FIS; Fisk, Ritvo, Ross, Haase, Murray, & Schlech, 1994), a multidimensional scale developed to assess the perceived impact of fatigue on a variety of daily activities. (The 4-item Vitality (VT) scale

of the SF-36 provides an additional independent measure of fatigue.) The response format and order of administration of some items was modified for the MSQLI-Field Test based on results of our pilot testing. Items are self-explanatory.

b)   Scoring (Standard 21-item version)

The items of the MFIS can be aggregated into three subscales (Physical, Cognitive, and Psychosocial), as well as into a total MFIS score. All items are scaled so that higher scores indicate a greater impact of fatigue on a patient's activities (i.e., no items are reverse scored).

Physical Subscale:
This scale can range from 0-36. It is computed by adding raw scores on the following items: 4+6+7+10+13+14+17+20+21.

Cognitive Subscale:
This scale can range from 0-40. It is computed by adding raw scores on the following items: 1+2+3+5+11+12+15+16+18+19.

Psychosocial Subscale:
This scale can range from 0-8. It is computed by adding raw scores on the following items: 8+9

Total MFIS Score:
The Total MFIS score can range from 0-84. It is computed by adding scores on the Physical+Cognitive+Psychosocial subscales.

c)   Scoring (5-item version)

The Modified Fatigue Impact Scale-5 item version (MFIS-5) consists of the 5 MFIS items correlating the most strongly with the total MFIS score (see Data Analysis section for methodologic details). The following items from the MFIS constitute the MFIS-5: Items 1, 9, 10, 17, and 19. Thus, items from all three subscales are represented. The MFIS-5 total score consists of the sum of the raw scores on these 5 items, and thus, can range from 0-20.

5.   MOS Pain Effects Scale (PES)

a)   Background

Pain and other unpleasant sensory symptoms are also under-recognized, but surprisingly common, symptoms of MS. In the MSQLI Field Test, 50.3% of the participants reported experiencing pain as a current symptom of their MS. Six items from the Medical Outcomes Study (Stewart and Ware, 1992) assessing the effects of pain on behavior and mood are incorporated in the MSLQI. (Note that the SF-36 Bodily Pain Scale (BP) provides an additional, independent measure of the severity and impact of pain on the patient's life.)

b)   **Administration**

These items are designed to be self-explanatory. Some patients may ask what to include in the definition of "pain." Patients should be told that pain is defined broadly, and can include any unpleasant sensory symptom related to MS, as well as pain unrelated to MS (e.g., headaches). Some patients may indicate that their pain and sensory symptoms have been severe, but that they have not allowed their symptoms to restrict their activities. These patients should circle the response that indicates how much their activities have *actually* been restricted, not how much they could have been restricted.

c)   **Scoring**

Raw scores on the 6 items that constitute this scale are simply added to form a PES total score. Thus, scores can range from 6-30. Items are scaled so that higher scores indicate a greater impact of pain on a patient's mood and behavior.

6.   **Sexual Satisfaction Scale (SSS)**

a)   **Background**

Changes in sexual functioning and sexual relationships are also common in MS, although health care practitioners are often unaware of these problems because many patients are reluctant to bring them up. Of the 25 items covering sexual function and satisfaction that were adapted from the Sexual History Form (Schover, Friedman, Weiler, Heiman, & LoPiccolo, 1982) for the MSQLI Field Test, only four sexual satisfaction items were retained for the final MSQLI. (Investigators and clinicians who are interested in problems in sexual function *per se* are directed to other sources (e.g., Stewart & Ware, 1992).)

b)   **Administration**

The items are generally self-explanatory. However, due to the sensitive nature of these questions, some patients may need to be reassured about the confidentiality of their responses. If a patient indicates that s/he is not sexually active and wonders whether s/he should respond to these items, the interviewer should say: "These questions concern your satisfaction with your sexual relationships in general, so please try to answer them as best you can."

c)   **Scoring**

Raw scores on the 4 sexual satisfaction items (Items 2-5) are summed to create a total score. Thus, this scale can range from 4-24. Higher scores indicate greater problems with sexual satisfaction.

7. Bladder Control Scale (BLCS)

a) Background and Administration

Bladder problems are a common and often disabling symptom in MS. The MSQLI Bladder Control Scale consists of 4 items written specifically for this study based on input from MS specialists (primarily nurses). Since bladder problems are often embarrassing to patients, they may need to be reassured about the confidentiality of their responses. On Item 3, if the patient indicates that s/he doesn't alter his/her activities but takes steps to ensure that bladder control isn't a problem (e.g., self-catheterizes prior to going out, calls to make sure that restrooms are readily available), this qualifies as altering activities because of bladder problems. Note also that Item 4 requests a rating of the overall impact of bladder problems on a patient's lifestyle, *not* the number of days or times that bladder problems interfered.

b) Scoring

Raw scores on the 4 items are summed to create a Bladder Control Scale (BLCS) total score. Scores can range from 0-22, with higher scores indicating greater bladder control problems.

8. Bowel Control Scale (BWCS)

a) Background and Administration

Bowel problems are also common in MS. The MSQLI Bowel Control Scale consists of 5 items written specifically for this study based on input from MS specialists (primarily nurses). As with the Bladder Control Scale, patients may need to be reassured about the confidentiality of their responses. On Item 4, if the patient indicates that s/he doesn't alter his/her activities but takes steps to ensure that bowel control isn't a problem (e.g., uses a suppository, calls to make sure that restrooms are readily available), this qualifies as altering activities due to bowel problems. Note also that Item 5 requests a rating of the overall impact of bowel problems on a patient's activities, *not* the number of days or times that bowel problems interfered.

b) Scoring

Raw scores on the 5 items are summed to create a Bowel Control Scale (BWCS) total score. Scores can range from 0-26, with higher scores indicating greater bowel control problems.

9. Impact of Visual Impairment Scale (IVIS)

a) Background and Administration

Visual problems are a common, often disabling, symptom in MS. In the MSQLI Field Test, 42.3% of the patients reported current visual problems. The Impact of Visual Impairment Scale

(IVIS) consists of 5 items selected from the Functional Capacities Assessment developed by the Michigan Commission for the Blind. These items assess the extent to which various activities dependent upon vision are affected by MS-related visual problems. They refer to any difficulties that a patient has seeing visual materials, difficulties that cannot be corrected with glasses, contact lenses, or other visual aids. They do not refer to difficulties processing visual information, i.e., difficulties that are more cognitive in nature. For Item 4, the patient should respond in terms of the difficulty s/he has watching TV or seeing faces from standard distances for these activities (i.e., at least several feet away).

b) Scoring

The VIS total score is computed by adding the raw scores on the 5 items composing this scale. Thus, it can range from 0-15, with higher scores indicating a greater impact of visual problems on daily activities.

10. Self-Reported Cognitive Dysfunction: Perceived Deficits Questionnaire (PDQ)

a) Background

Cognitive dysfunction occurs frequently in MS. Concentration and recent memory are the functions affected most often, but executive functions (e.g., planning, problem-solving) and other cognitive domains can also be affected. The MSQLI includes the Perceived Deficits Questionnaire (PDQ; Sullivan, Edgley, & Dehoux, 1990) to assess perceived cognitive deficits from the patient's perspective. (A number of items on this scale were derived from earlier work by Mateer and her colleagues (Mateer, Sohlberg, & Crinean, 1987).) Since patients' *perceptions* of their cognitive function may not be concordant with their *objectively-measured* function, scores on measures of perceived cognitive function should be interpreted cautiously. Administration of objective neuropsychological measures is also strongly encouraged.

b) Administration

Minor modifications in the response format and order of administration of some PDQ items was made to improve ease of comprehension, based on results of our pilot testing. Most items are self-explanatory. For Item 19, patients who are not taking any medications should mark "0".

c) Scoring (Standard 20-item version)

The PDQ was designed to have four 5-item subscales: Attention/Concentration, Retrospective Memory, Prospective Memory, and Planning/Organization. Although these were rationally-developed, Sullivan and his colleagues (1990) report that they confirmed this 4-factor structure empirically. In contrast, factor analysis of our Field Test data yielded only a single general factor, although this may in part be attributable to methodological differences between these two studies. Scoring procedures for Sullivan et al.'s (1990) 4 subscales are given here, but in light of our failure to confirm this factor structure, caution should be used in interpreting subscale scores. A total

PDQ score can also be computed. Higher scores indicate greater perceived cognitive impairment.

Attention/Concentration Subscale:
>Raw scores on Items 1+5+9+13+17 are added to compute this subscale score. Consequently, scores can range from 0-20.

Retrospective Memory Subscale:
>Raw scores on Items 2+6+10+14+18 are added to compute this score. Scores can range from 0-20.

Prospective Memory Subscale:
>Raw scores on Items 3+7+11+15+19 are added to compute this score. Scores can range from 0-20.

Planning/Organization Subscale:
>Raw scores on Items 4+8+12+16+20 are added to compute this score. Scores can range from 0-20.

PDQ Total Score:
>The PDQ Total Score is computed by adding raw scores for all of the PDQ items (or all 4 subscale scores) together. Thus, it can range from 0-80.

d) Scoring (5-item version)

The Perceived Deficits Questionnaire-5 item version (PDQ-5) consists of the 5 PDQ items correlating the most strongly with the total PDQ score (see Data Analysis section for methodologic details). The following items from the PDQ constitute the PDQ-5: Items 4, 9, 11, 14, and 16. Thus, items from all four subscales are represented. The PDQ-5 total score consists of the sum of the raw scores on these 5 items, and thus, can range from 0-20.

11. Mental Health Inventory (MHI)

a) Background

Most MS patients experience significant emotional distress at some point over the course of their illness. The Mental Health Inventory (MHI) is a widely-accepted measure of overall emotional functioning developed by Veit and Ware (1983) for the Rand Health Insurance Experiment. It covers a wide range of negative and positive emotions, not just psychopathology. The 18-item version of the MHI is included in the MSQLI because it is reasonably brief, reliable, and preserves the subscale structure.

b)   **Administration**

Most items are self-explanatory. Note that the 5-item Mental Health Scale (MH) on the SF-36 is drawn from the MHI.

c)   **Scoring (Standard 18-item version)**

The MHI has 4 subscales (Anxiety, Depression, Behavioral Control, and Positive Affect) and 1 total score. The subscale and total scores range from 0-100, with higher scores indicating better mental health.

MHI-18 Total Score:
     Assign raw scores to Items #1, 3, 5, 7, 8, 10, 13, and 15 as follows:
          All of the time(1) =   6
          Most of the time(2) =   5
          A good bit of the time(3) =   4
          Some of the time(4) =   3
          A little of the time(5) =   2
          None of the time(6) =   1
     No conversion is needed for the remaining items.

     After making the above conversions, compute the Mean MHI Score as follows:
          Mean MHI Raw Score = [Σ(Items 1+2+3+....18)]/18
          Thus, the mean MHI Raw Score will range from 1-6.
     Next, compute the MHI Total Score (a transformed score) as follows:
          MHI Total Score = [(Mean MHI-1)*100]/5
          Thus, scores on this scale can range from 0-100.
     Note: If the patient skipped more than 9 items, the total score should not be computed.

Anxiety Subscale (MHA):
     Assign raw scores to Item #10 as follows:
          All of the time(1) =   6
          Most of the time(2) =   5
          A good bit of the time(3) =   4
          Some of the time(4) =   3
          A little of the time(5) =   2
          None of the time(6) =   1
     No conversion is needed for Items #4, 6, 11, and 18.

     After making the above conversions, compute the mean subscale score for the Anxiety Subscale as follows:
          Mean Subscale Score = [Σ(Items 4+6+10+11+18)]/5
          Thus, the mean subscale score will range from 1-6.
     Next, compute the MHA Total Score (a transformed score) as follows:

MHA Total Score = [(Mean Anxiety Subscale Score-1)*100]/5

Thus, scores on this scale can range from 0-100.

Note: If the patient skipped more than 2 items, the Anxiety Subscale score should not be computed.

Depression Subscale (MHD):

No conversion of raw scores is needed.

Compute the mean subscale score for the Anxiety Subscale as follows:

Mean Subscale Score = [Σ(Items 2+9+12+14)]/4

Thus, the mean subscale score will range from 1-6.

Next, compute the MHD Total Score (a transformed score) as follows:

MHD Total Score = [(Mean Depression Subscale Score-1)*100]/5

Thus, scores on this scale can range from 0-100.

Note: If the patient skipped more than 2 items, the Depression Subscale score should not be computed.

Behavior Control Subscale (MHC):

Assign raw scores to Items #5 and 8 as follows:

All of the time(1) =	6
Most of the time(2) =	5
A good bit of the time(3) =	4
Some of the time(4) =	3
A little of the time(5) =	2
None of the time(6) =	1

No conversion is needed for Items #16 and 17.

After making the above conversions, compute the mean subscale score for the Behavior Control Subscale as follows:

Mean Subscale Score = [Σ(Items 5+8+16+17)]/4

Thus, the mean subscale score will range from 1-6.

Next, compute the MHC Total Score (a transformed score) as follows:

MHC Total Score = [(Mean Behavior Control Subscale Score-1)*100]/5

Thus, scores on this scale can range from 0-100.

Note: If the patient skipped more than 2 items, the Behavior Control Subscale score should not be computed.

Positive Affect Subscale (MHP):

Assign raw scores to Items #1, 7, 13, and 15 as follows:

All of the time(1) =	6
Most of the time(2) =	5
A good bit of the time(3) =	4
Some of the time(4) =	3
A little of the time(5) =	2
None of the time(6) =	1

After making the above conversions, compute the mean subscale score for the Positive Affect Subscale as follows:

Mean Subscale Score = [Σ(Items 1+7+13+15)]/4

Thus, the mean subscale score will range from 1-6.

Next, compute the MHP Total Score (a transformed score) as follows:

MHP Total Score = [(Mean Positive Affect Subscale Score-1)*100]/5

Thus, scores on this scale can range from 0-100.

Note: If the patient skipped more than 2 items, the Positive Affect Subscale score should not be computed.

d) Scoring (5-item version)

Five MHI items (Items 4, 7, 9, 15, and 17) are also on the SF-36. These are the 5 items that correlated most highly with the full-length (38-item) MHI summary score (cf. Stewart & Ware, 1994). The MHI-5 Total Score should be computed as described above for the Mental Health (MH) subscale of the SF-36.

12. Modified MOS Social Support Survey (MSSS)

a) Background

The Social Support Survey is a brief multidimensional measure of perceived social support developed by Sherbourne and Stewart (1991) based on the Medical Outcomes Study. Two additional items from the MOS SSS (one item on network size and one additional perceived support item that was not included in the total score) were included in the Field Test but are not included in the final MSQLI. Consequently, the MSQLI version is referred to as the Modified SSS. Note that the MSSS refers to *perceived*, not actual, support and that this refers to support from all sources (i.e., all types of support do not have to be available from the same person).

b) Administration

Although the time frame is not given, patients who ask for a time frame should be instructed to think of the support they had available during the past 4 weeks. The following clarifications may also be useful:

Items 1 and 4: If a patient indicates that s/he has never been confined to bed (or always drives himself/herself to the doctor), ask him/her to answer based on how often s/he thinks that someone would be available if s/he *were* confined to bed (or needed a ride to the doctor).

Item 6: "Have a good time with" can refer to getting together with someone either in person, or by phone, through the Internet, etc. and doing something enjoyable.

c) Scoring (Standard 18-item version)

The MSSS yields 4 subscale scores (Tangible Support, Emotional/Informational Support, Affectionate Support, and Positive Social Interaction), as well as a total score. Each of these scores ranges from 0-100, with higher scores indicating greater perceived support. No reverse scoring is needed.

Tangible Support Subscale (TAN):
Compute raw score by adding scores on Items 1+4+11+13.
Raw scores on this scale range from 4-20.
Compute transformed score as follows: [(Raw score-4)/16] x 100

Emotional/Informational Support Subscale (EMI):
Compute raw score by adding scores on Items 2+3+7+8+12+14+15+17.
Raw scores on this scale range from 8-40.
Compute transformed score as follows: [(Raw score-8)/32] x 100

Affectionate Support Subscale (AFF):
Compute raw score by adding scores on Items 5+9+18.
Raw scores on this scale range from 3-15.
Compute transformed score as follows: [(Raw score-3)/12] x 100

Positive Social Interaction Subscale (POS):
Compute raw score by adding scores on Items 6+10+16.
Raw scores on this scale range from 3-15.
Compute transformed score as follows: [(Raw score-3)/12] x 100

MSSS Total Score:
The MSSS Total Score is computed as follows:
(TAN+EMI+AFF+POS)/4

d) Scoring (5-item version)

The Modified Social Support Survey-5 item version (MSSS-5) consists of the 5 MSSS items correlating the most strongly with the total MSSS score (see Data Analysis section for methodologic details). The following items from the MSSS constitute the MSSS-5: Items 4, 6, 9, 11, and 17. Thus, items from all four subscales are represented. The MSSS-5 total score can be computed as follows:

Compute raw score by adding scores on these 5 items
Raw scores on this scale range from 5-25.
Compute transformed score as follows: [(Raw score-5)/20] x 100

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Patient's Name: _____   **Date:** ____/____/____
                                                          month day year

ID#: _____   **Test#:**   **1   2   3   4**

HEALTH STATUS QUESTIONNAIRE (SF-36)

INSTRUCTIONS
This survey asks for your views about your health and daily activities. If you are marking your own answers, please underline circle the appropriate responses (0, 1, 2,...). If you need help in marking your responses, tell the interviewer the number of the best response (or what to fill in). Please answer every question. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

1.   In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

2.   For each statement please circle the one number that indicates how true or false that statement is for you.

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
a) I seem to get sick a little easier than other people.	1	2	3	4	5
b) I am as healthy as anybody I know.	1	2	3	4	5
c) I expect my health to get worse.	1	2	3	4	5
d) My health is excellent.	1	2	3	4	5

3.   Compared to one year ago, how would you rate your health in general now?

Much Better	Somewhat Better	Same	Somewhat Worse	Much Worse
1	2	3	4 5	

4. Now, think about the activities you might do on a typical day. Does <u>your health</u> limit you in these activities? If so, <u>how much</u>? Please circle 1, 2 or 3 for each item to indicate how much your health limits you.

	Yes, Limited <u>A Lot</u>	Yes, Limited <u>A Little</u>	No, Not Limited <u>At All</u>
a) <u>Vigorous activities,</u> such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b) <u>Moderate activities,</u> such as moving a table, pushing a vacuum cleaner or bowling, or playing golf	1	2	3
c) Lifting or carrying groceries	1	2	3
d) Climbing <u>several</u> flights of stairs	1	2	3
e) Climbing <u>one</u> flight of stairs	1	2	3
f) Bending, kneeling, or stooping	1	2	3
g) Walking <u>more than a mile</u>	1	2	3
h) Walking <u>several blocks</u>	1	2	3
i) Walking <u>one block</u>	1	2	3
j) Bathing and dressing yourself	1	2	3

5. During the <u>past 4 weeks,</u> have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health?</u> Please circle "1" (Yes) or "2" (No) for each item.

	<u>YES</u>	<u>NO</u>
a) Cut down on the <u>amount of time</u> you spent on work or other activities	1	2
b) <u>Accomplished less than you would like</u>	1	2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Please circle "1" (Yes) or "2" (No) for each item.

	YES	NO
c) Were limited in the kind of work or other activities	1	2
d) Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

6. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
1	2	3	4	5	6

7. During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

8. During the past 4 weeks, have you had the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? Please circle "1" (Yes) or "2" (No) for each item.

	YES	NO
a) Cut down on the amount of time you spent on work or other activities	1	2
b) Accomplished less than you would like	1	2
c) Did do work or other activities less carefully than usual	1	2

9. During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

10. The next set of questions is about how you <u>feel</u> and how things have been with you during the <u>past 4 weeks</u>. For each question, please circle the one number for the answer that comes closest to the way you have been feeling.

How much of the time
during the <u>past 4 weeks</u>...

	All of the <u>Time</u>	Most of the <u>Time</u>	A Good Bit of <u>the Time</u>	Some of the <u>Time</u>	A Little of the <u>Time</u>	None of the <u>Time</u>
a) did you feel full of pep?	1	2	3	4	5	6
b) have you been a very nervous person?	1	2	3	4	5	6
c) have you felt so down in the dumps nothing could cheer you up?	1	2	3	4	5	6
d) have you felt calm and peaceful?	1	2	3	4	5	6
e) did you have a lot of energy?	1	2	3	4	5	6
f) have you felt down hearted and blue?	1	2	3	4	5	6
g) did you feel worn out?	1	2	3	4	5	6
h) have you been a happy person?	1	2	3	4	5	6
i) did you feel tired?	1	2	3	4	5	6

11. Finally, <u>during the past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> intefered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

Patient's Name: _____ **Date:** ____/____/____
                                                    month day year

ID#: _____ **Test#:**   1   2   3   4

MODIFIED FATIGUE IMPACT SCALE (MFIS)

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and then circle the one number that best indicates how often fatigue has affected you in this way during the past 4 weeks.   (If you need help in marking your responses, tell the interviewer the number of the best response.) Please answer every question. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

**Because of my fatigue
during the past 4 weeks....**

		Never	Rarely	Sometimes	Often	Almost always
1.	I have been less alert.	0	1	2	3	4
2.	I have had difficulty paying attention for long periods of time.	0	1	2	3	4
3.	I have been unable to think clearly.	0	1	2	3	4
4.	I have been clumsy and uncoordinated.	0	1	2	3	4
5.	I have been forgetful.	0	1	2	3	4
6.	I have had to pace myself in my physical activities.	0	1	2	3	4
7.	I have been less motivated to do anything that requires physical effort.	0	1	2	3	4

**Because of my fatigue
during the past 4 weeks....**

		Never	Rarely	Sometimes	Often	Almost always
8.	I have been less motivated to participate in social activities.	0	1	2	3	4
9.	I have been limited in my ability to do things away from home.	0	1	2	3	4
10.	I have had trouble maintaining physical effort for long periods.	0	1	2	3	4
11.	I have had difficulty making decisions.	0	1	2	3	4
12.	I have been less motivated to do anything that requires thinking.	0	1	2	3	4
13.	my muscles have felt weak.	0	1	2	3	4
14.	I have been physically uncomfortable.	0	1	2	3	4
15.	I have had trouble finishing tasks that require thinking.	0	1	2	3	4
16.	I have had difficulty organizing my thoughts when doing things at home or at work.	0	1	2	3	4
17.	I have been less able to complete tasks that require physical effort.	0	1	2	3	4
18.	my thinking has been slowed down.	0	1	2	3	4
19.	I have had trouble concentrating.	0	1	2	3	4

**Because of my fatigue
during the <u>past 4 weeks</u>....**

		<u>Never</u>	<u>Rarely</u>	<u>Sometimes</u>	<u>Often</u>	**Almost** <u>always</u>
20.	**I have limited my physical activities.**	**0**	**1**	**2**	**3**	**4**
21.	**I have needed to rest more often or for longer periods.**	**0**	**1**	**2**	**3**	**4**

Patient's Name: _____   **Date:** _____/_____/_____
                                                                month day year

ID#: _____   **Test#:**   1   2   3   4

MODIFIED FATIGUE IMPACT SCALE - 5-ITEM VERSION (MFIS-5)

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and then circle the one number that best indicates how often fatigue has affected you in this way during the past 4 weeks.   (If you need help in marking your responses, tell the interviewer the number of the best response.) Please answer every question. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

Because of my fatigue during the past 4 weeks....

		Never	Rarely	Sometimes	Often	Almost always
1.	I have been less alert.	0	1	2	3	4
2.	I have been limited in my ability to do things away from home.	0	1	2	3	4
3.	I have had trouble maintaining physical effort for long periods.	0	1	2	3	4
4.	I have been less able to complete tasks that require physical effort.	0	1	2	3	4
5.	I have had trouble concentrating.	0	1	2	3	4

MOS PAIN EFFECTS SCALE (PES)

INSTRUCTIONS
Individuals with MS can sometimes experience unpleasant sensory symptoms as a result of their MS (e.g., pain, tingling, burning). The next set of questions covers pain and other unpleasant sensations, and how they affect you. Please <u>circle the one number</u> (0, 1, 2,...) that best indicates the extent to which your sensory symptoms (including pain) interfered with that aspect of your life during the <u>past 4 weeks</u>. If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response (or what to fill in). <u>Please answer every question</u>. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

During the <u>past 4 weeks</u>,
how much did these symptoms
interfere with your...

		Not at all	A little	Moderately	Quite a bit	To an extreme degree
1.	mood	1	2	3	4	5
2.	ability to walk or move around	1	2	3	4	5
3.	sleep	1	2	3	4	5
4.	normal work (both outside your home and at home)	1	2	3	4	5
5.	recreational activities	1	2	3	4	5
6.	enjoyment of life	1	2	3	4	5

Patient's Initials: _____   **Date:** _____/_____/_____
                                                            month day year

ID#: _____   **Test#:**   **1   2   3   4**

SEXUAL SATISFACTION SCALE (SSS)

INSTRUCTIONS
The next series of questions concerns your intimate relationships and your satisfaction with your sex life. Many of these questions are very personal, but this is an important topic to cover. If you are marking your own answers, please <u>circle</u> the appropriate response (0, 1, 2,...). If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response. <u>Please answer every question</u>. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

1.   **Do you have a relationshipwith one primary partner?**

No [GO TO NEXT QUESTIONNAIRE]	**0**
Yes	**1**

2.   **During the <u>past 4 weeks</u>, how satisfied have you been with the amount of affection expressed physically in your relationship?**

Extremely Satisfied	Moderately Satisfied	Slightly Satisfied	Slightly Dissatisfied	Moderately Dissatisfied	Extremely Dissatisfied
1	2	3	4	5	6

3.   **During the <u>past 4 weeks</u>, how satisfied have you been with the <u>variety</u> of sexual activities you engage in with your partner?**

Extremely Satisfied	Moderately Satisfied	Slightly Satisfied	Slightly Dissatisfied	Moderately Dissatisfied	Extremely Dissatisfied
1	2	3	4	5	6

4.   **During the <u>past 4 weeks</u>, how satisfied have you been with your sexual relationship in general?**

Extremely Satisfied	Moderately Satisfied	Slightly Satisfied	Slightly Dissatisfied	Moderately Dissatisfied	Extremely Dissatisfied
1	2	3	4	5	6

5. **How satisfied do you think your partner has been with your sexual relationship in general, during the <u>past 4 weeks</u>?**

Extremely Satisfied	Moderately Satisfied	Slightly Satisfied	Slightly Dissatisfied	Moderately Dissatisfied	Extremely Dissatisfied
1	2	3	4	5	6

Patient's Name: _____   **Date:** _____/_____/_____
                                                          month day year

ID#: _____   **Test#:**   1   2   3   4

BLADDER CONTROL SCALE (BLCS)

INSTRUCTIONS
The next set of questions concerns bladder problems that can occur in MS. Many of these questions are very personal, but this is an important topic to cover. If you are marking your own answers, please <u>circle</u> the appropriate response (0, 1, 2,...) based on your bladder function during the <u>past 4 weeks</u>. If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response. <u>Please answer every question</u>. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

During the <u>past 4 weeks</u>,
how often have you...

		Not at all	Once	Two to four times	More than weekly but not daily	Daily
1.	lost control of your bladder or had an accident?	0	1	2	3	4
2.	<u>almost</u> lost control of your bladder or had an accident?	0	1	2	3	4
3.	altered your activities because of bladder problems?	0	1	2	3	4

4.   During the <u>past 4 weeks</u>, how much have bladder problems restricted your overall lifestyle? (Please circle one number.)

Not at all										Severely
0	1	2	3	4	5	6	7	8	9	10

Patient's Name: _____   **Date:** ____/____/____
                                                                                              month day year

ID#: _____   **Test#:**   1   2   3   4

BOWEL CONTROL SCALE (BWCS)

INSTRUCTIONS
The next set of questions concerns bowel problems that can occur in MS. Many of these questions are very personal, but this is an important topic to cover. If you are marking your own answers, please <u>circle</u> the appropriate response (0, 1, 2,...) based on your bowel function during the <u>past 4 weeks</u>. If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response. <u>Please answer every question</u>. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

**During the <u>past 4 weeks</u>,
how often have you...**

		Not at all	Once	Two to four times	More than weekly but not daily	Daily
1.	been constipated?	0	1	2	3	4
2.	lost control of your bowels or had an accident?	0	1	2	3	4
3.	<u>almost</u> lost control of your bowels or almost had an accident ?	0	1	2	3	4
4.	altered your activities because of bowel control problems?	0	1	2	3	4

5.   During the <u>past 4 weeks</u>, how much have bowel problems restricted your overall lifestyle? (Please circle <u>one</u> number.)

Not at all										Severely
0	1	2	3	4	5	6	7	8	9	10

Patient's Name: _____   **Date:** ____/____/____
                                                    month day year

ID#: _____   **Test#:**   1   2   3   4

IMPACT OF VISUAL IMPAIRMENT SCALE (IVIS)

INSTRUCTIONS
The following questions concern your vision and how any visual problems have affected your ability to do your daily activities. If you are marking your own answers, please <u>circle</u> the appropriate response (0, 1, 2,...) based on how your vision has been during the <u>past 4 weeks</u>. If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response. <u>Please answer every question</u>. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

During the <u>past 4 weeks</u>,
how difficult did you find it to...

	Not at all difficult	Somewhat difficult	Extremely difficult	Could not do due to visual problems
1. read or access personal letters or notes?	0	1	2	3
2. read or access printed materials, such as books, magazines, newspaper, etc.?	0	1	2	3
3. read or access dials, such as on stoves, thermostats, etc.?	0	1	2	3
4. watch television or identify faces from a distance?	0	1	2	3
5. identify house numbers, street signs, etc.?	0	1	2	3

Patient's Name: _____   **Date:** ____/____/____
                                                      month day year

ID#: _____   **Test#:**   1   2   3   4

PERCEIVED DEFICITS QUESTIONNAIRE (PDQ)

INSTRUCTIONS
Everyone at some point experiences problems with memory, attention, or concentration,
but these problems may occur more frequently for individuals with neurologic diseases like
MS. The following questions describe several situations in which a person may encounter
problems with memory, attention or concentration. If you are marking your own answers,
please circle the appropriate response (0, 1, 2,...) based on your cognitive function during
the past 4 weeks. If you need help in marking your responses, tell the interviewer the
number of the best response. Please answer every question. If you are not sure which
answer to select, please choose the one answer that comes closest to describing you. The
interviewer can explain any words or phrases that you do not understand.

During the past 4 weeks,
how often did you....

		Never	Rarely	Some-times	Often	Almost always
1.	lose your train of thought when speaking?	0	1	2	3	4
2.	have difficulty remembering the names of people, even ones you have met several times?	0	1	2	3	4
3.	forget what you came into the room for?	0	1	2	3	4
4.	have trouble getting things organized?	0	1	2	3	4
5.	have trouble concentrating on what people are saying during a conversation?	0	1	2	3	4
6.	forget if you had already done something?	0	1	2	3	4
7.	miss appointments and meetings you had scheduled?	0	1	2	3	4

**During the past 4 weeks,
how often did you....**

		Never	Rarely	Some-times	Often	Almost always
8.	have difficulty planning what to do in the day?	0	1	2	3	4
9.	have trouble concentrating on things like watching a television program or reading a book?	0	1	2	3	4
10.	forget what you did the night before?	0	1	2	3	4
11.	forget the date unless you looked it up?	0	1	2	3	4
12.	have trouble getting started, even if you had a lot of things to do?	0	1	2	3	4
13.	find your mind drifting?	0	1	2	3	4
14.	forget what you talked about after a telephone conversation?	0	1	2	3	4
15.	forget to do things like turn off the stove or turn on your alarm clock?	0	1	2	3	4
16.	feel like your mind went totally blank?	0	1	2	3	4
17.	have trouble holding phone numbers in your head, even for a few seconds?	0	1	2	3	4
18.	forget what you did last weekend?	0	1	2	3	4
19.	forget to take your medication?	0	1	2	3	4
20.	have trouble making decisions?	0	1	2	3	4

Patient's Name: _____   **Date:**   ____/____/____
                                                        month day year

ID#:   _____   **Test#:**   1   2   3   4

PERCEIVED DEFICITS QUESTIONNAIRE - 5-ITEM VERSION (PDQ-5)

INSTRUCTIONS
Everyone at some point experiences problems with memory, attention, or concentration, but these problems may occur more frequently for individuals with neurologic diseases like MS. The following questions describe several situations in which a person may encounter problems with memory, attention or concentration. If you are marking your own answers, please <u>circle</u> the appropriate response (0, 1, 2,...) based on your cognitive function during the <u>past 4 weeks</u>. If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response. <u>Please answer every question.</u> If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

**During the <u>past 4 weeks</u>,
how often did you....**

		Never	**Rarely**	**Some-times**	**Often**	**Almost always**
1.	**have trouble getting things organized?**	**0**	**1**	**2**	**3**	**4**
2.	**have trouble concentrating on things like watching a television program or reading a book?**	**0**	**1**	**2**	**3**	**4**
3.	**forget the date unless you looked it up?**	**0**	**1**	**2**	**3**	**4**
4.	**forget what you talked about after a telephone conversation?**	**0**	**1**	**2**	**3**	**4**
5.	**feel like your mind went totally blank?**	**0**	**1**	**2**	**3**	**4**

Patient's Name: _____   **Date:** ____/____/____
           F   M   L   month day year

ID#: _____   **Test#:** 1 2 3 4

MENTAL HEALTH INVENTORY (MHI)

The next set of questions are about how you feel, and how things have been for you during the <u>past 4 weeks</u>. If you are marking your own answers, please <u>circle</u> the appropriate response (0, 1, 2,...). If you need help in marking your responses, <u>tell the interviewer the number</u> of the best response. <u>Please answer every question</u>. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

**During the <u>past 4 weeks</u>,
how much of the time...**

	All of the time	Most of the time	A good bit of the time	Some of the time	A little bit of the time	None of the time
1. has your daily life been full of things that were interesting to you?	1	2	3	4	5	6
2. did you feel depressed?	1	2	3	4	5	6
3. have you felt loved and wanted?	1	2	3	4	5	6
4. have you been a very nervous person?	1	2	3	4	5	6
5. have you been in firm control of your behavior, thoughts, emotions, feelings?	1	2	3	4	5	6

During the <u>past 4 weeks</u>, how much of the time...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little bit of the time	None of the time
6. have you felt tense or high-strung?	1	2	3	4	5	6
7. have you felt calm and peaceful?	1	2	3	4	5	6
8. have you felt emotionally stable?	1	2	3	4	5	6
9. have you felt downhearted and blue?	1	2	3	4	5	6
10. were you able to relax without difficulty?	1	2	3	4	5	6
11. have you felt restless, fidgety, or impatient?	1	2	3	4	5	6
12. have you been moody, or brooded about things?	1	2	3	4	5	6
13. have you felt cheerful, light-hearted?	1	2	3	4	5	6
14. have you been in low or very low spirits?	1	2	3	4	5	6
15. were you a happy person?	1	2	3	4	5	6

During the past 4 weeks, how much of the time...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little bit of the time	None of the time
16. did you feel you had nothing to look forward to?	1	2	3	4	5	6
17. have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
18. have you been anxious or worried?	1	2	3	4	5	6

Patient's Name: _____   **Date:** ____/____/____
<div align="right">month day year</div>

ID#: _____   **Test#:**   1   2   3   4

<div align="center">

MOS MODIFIED SOCIAL SUPPORT SURVEY (MSSS)

</div>

INSTRUCTIONS

People sometimes look to others for companionship, assistance, or other types of support. This questionnaire covers the types of support that would be available to you if you needed it. If you are marking you own answers, please underline **circle the appropriate response (0, 1, 2,...) based on the support available to you during the** underline **past 4 weeks. If you need help in marking your responses,** underline **tell the interviewer the number** of the best response (or what to fill in). Please answer every question. **If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.**

How often is someone available...

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
1. to help you if you are confined to bed?	1	2	3	4	5
2. to listen to you when you need to talk?	1	2	3	4	5
3. to give you good advice about a crisis?	1	2	3	4	5
4. to take you to the doctor if you need to go?	1	2	3	4	5
5. to show you love and affection?	1	2	3	4	5
6. to have a good time with?	1	2	3	4	5
7. to give you information to help you understand a situation?	1	2	3	4	5
8. to confide in or talk to about yourself or your problems?	1	2	3	4	5

How often is someone available...

		None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
9.	to hug you?	1	2	3	4	5
10.	to get together with for relaxation?	1	2	3	4	5
11.	to prepare your meals if you are unable to do it yourself?	1	2	3	4	5
12.	whose advice you really want?	1	2	3	4	5
13.	to help with daily chores if you are sick?	1	2	3	4	5
14.	to share your private worries and fears with?	1	2	3	4	5
15.	to turn to for suggestions about how to deal with a personal problem?	1	2	3	4	5
16.	to do something enjoyable with?	1	2	3	4	5
17.	to understand your problems?	1	2	3	4	5
18.	to love and make you feel wanted?	1	2	3	4	5

Patient's Name: _____   **Date:**   ____/____/____
                                                                     month day year

ID#: _____   **Test#:**   **1   2   3   4**

MOS MODIFIED SOCIAL SUPPORT SURVEY - 5-ITEM VERSION (MSSS-5)

INSTRUCTIONS

People sometimes look to others for companionship, assistance, or other types of support. This questionnaire covers the types of support that would be available to you if you needed it. If you are marking you own answers, please <u>circle</u> **the appropriate response (0, 1, 2,...) based on the support available to you during the** <u>past 4 weeks</u>**. If you need help in marking your responses,** <u>tell the interviewer the number</u> **of the best response (or what to fill in).** <u>Please answer every question</u>**. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.**

How often is someone available...

		None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
1.	**to take you to the doctor if you need to go?**	1	2	3	4	5
2.	**to have a good time with?**	1	2	3	4	5
3.	**to hug you?**	1	2	3	4	5
4.	**to prepare your meals if you are unable to do it yourself?**	1	2	3	4	5
5.	**to understand your problems?**	1	2	3	4	5